Improving access to and engagement with mental health services among young people from refugee backgrounds: Service user and provider perspectives

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Abstract

Little research has been conducted worldwide on the experiences that children and young people from refugee backgrounds have with mental health services, despite evidence that children and young people from refugee backgrounds have significant vulnerability to the development of mental health problems and to suicidal behaviour and that those with mental ill-health typically underutilise services. The authors were particularly interested in barriers and facilitators to service access and engagement, and conducted two qualitative research projects to improve understanding of the issues – the first with service providers experienced in the refugee area and the second with young refugee service users. The aim of this project was to compare the perspectives of professionals and service users and to identify similarities and differences.

The perspectives of the service users and providers were strikingly similar. The analysis identified 21 implications for policy makers, agencies and practitioners, which ranged from issues concerning cultural sensitivity, background matching and mental health literacy to accessibility, setting boundaries and expectations and implementing a holistic and outreach approach.

There is a range of specific, practical measures that policy makers and service providers can introduce to enhance access to and engagement with mental health services for young people from refugee backgrounds.

Keywords: mental health service, access, utilization, young refugee, asylum seeker, barriers, facilitators

Introduction

The prevalence and persistence of religious, racial, political and other forms of persecution, conflict, generalized violence, and human rights violations in the twenty-first century has seen millions of people of all ages flee their countries of origin and many to seek permanent protection (UNHCR, 2016) . The flow continues and global forced displacement has increased in 2015, with record-high numbers : "(b)y the end of the year, 65.3 million individuals were forcibly displaced worldwide" (UNHCR, 2016, p.2) . This is an increase of more than 50 per cent in five years and were the highest levels of forced displacement since the aftermath of the World War II (UNHCR, 2016).

The rising global burden of forced migration is increasingly recognised as an important issue in global and international public health (Siriwardhana, Sheik Ali, Roberts, & Stewart, 2014). There is some degree of evidence that children and young people from a refugee background have greater vulnerability to the development of mental health problems and to suicidal behaviour (Vijayakumar & Jotheeswaran, 2010). However, a recent systematic literature review by the authors (E. Colucci, Szwarc, Minas, Paxton, & Guerra, 2014) highlighted that research about use of mental health services in this population is very scarce. Of the 1028 references retrieved, only 11 were reports of original research about this topic.

The small number of published studies suggests that children and young people from a refugee background are underrepresented as clients of mental health services and those who attend often engage tenuously (de Anstiss, Ziaian, Procter, Warland, & Baghurst, 2009; Ellis, Miller, Baldwin, & Abdi, 2011). Low or 'lower than expected' levels of service

use may in part reflect reduced levels of need for service and a great degree of resilience (e.g. (Siriwardhana et al., 2014; Steel, Silove, Chey, Bauman, & Phan, 2005; Weine et al., 2000)). Nevertheless, studies that have measured mental health needs and service utilisation levels have found that the majority of young refugees who have significant mental health needs do not access services (e.g., (Bean, Eurelings-Bontekoe, Mooijaart, & Spinhoven, 2006; Ziaian, 2013). It is therefore important to understand factors that might improve or impede mental health service utilisation and responsiveness and use this evidence to improve policies, programs and therapeutic practices. This need was also identified in our Delphi study to establish a mental health research agenda (Minas, Colucci, Szwarc, Paxton, & Guerra, Forthcoming), in which exploration of barriers and facilitators to access and engagement with mental health services is considered a key research priority. The authors therefore undertook two studies to identify factors that may impede or enable access to and engagement with services, from the perspectives of service providers experienced in the area (Study 1) and young service users from refugee backgrounds (Study 2).

Three experts' roundtables were also organised: pre-data collection; post-Study 1 to discuss preliminary findings; and post-Study 2 to discuss the service and practice implications of the project findings.

This article reports the findings from a comparison of professionals' and service users' perspectives for the purpose of identifying similarities and differences and the implications of the findings for improving access and engagement with mental health services among young people from refugee backgrounds.

Methods

The two qualitative studies were designed, carried out and analysed separately and independently. Details of both study methods are provided elsewhere (E. Colucci, Szwarc, Minas, Paxton, & Guerra, 2015; Valibhoy, Kaplan, & Szwarc, in press). The two studies utilised qualitative in-depth individual and group interviews based on semi-structured ad-hoc interview guides to explore their experiences with services, particularly barriers and facilitators to access and engagement. Study 1 participants were service providers with direct experience in youth and refugee mental health. Study 2 participants were young people (18 – 25 year olds) who had been granted refugee status and had received services from a mental health professional. Fifteen focus groups (Study 1, with min 5-max 10 participants in each group for a total of 115 participants) and 21 individual interviews (16 in Study 2 and five in Study 1) were conducted across the two studies, with a total of 131 participants.

Multiple recruitment methods were used including circulation of flyers inviting participation, (e)mail-outs, presentations, phone calls to agencies and snowball sampling. Of the 16 participants in Study 2, three required (pre-briefed and qualified) interpreters, both for the informed consent phase and the interview. Recruitment and data collection continued until saturation was reached and no major new themes were arising.

Verbatim transcripts and notes were analysed guided by the thematic analysis steps of coding, clustering, searching and refining themes and subthemes, then writing about themes with identification of verbatim excerpts that illustrated the themes (e.g. (Braun & Clarke, 2006). Independent raters were involved for validity and rigour.

The findings from Study 1(E. Colucci, Szwarc, Minas, Paxton, & Guerra, 2011; E. Colucci et al., 2015) and Study 2 (Valibhoy et al., in press) have been independently reported. The Study 1 PI (EC) and the study 2 PI (MV) then independently conducted a systematic comparison of the two sets of findings. They categorised each key theme and sub-theme as: a) Same or very similar; b) Somewhat similar; c) Mentioned in one study but not the other; or d) Different [i.e. there were different views concerning the issue at hand expressed by professionals (Study 1) and service users (Study 2)]. Following this independent analysis, the ratings were compared. Where necessary, the raw data were cross-checked to accurately rate the theme. The overall inter-rater agreement was 95.2%. Where agreement could not be reached on the appropriate rating for a particular theme a third rater (JS) was involved to reach final agreement.
The following section presents the implications for policy and practice, with reference to relevant literature.

Compliance with Ethical Standards : The two studies were granted independent ethics approval by the University of Melbourne Human Research Ethics Committee, VFST Institutional Ethics Committee and Melbourne Health Human Research Ethics Committee.

Results and Discussion

Table 1 shows the main themes and sub-themes that emerged in Study 1 and Study 2 and illustrative quotes from the transcripts, the implications for policy and practice that were derived from these themes, and the extent of similarity of perspectives and implications between service providers and service users.

INSERT TABLE 1

Because service providers and service users may be expected to have different understanding of and views about mental health, illness and treatment, the first implication was that practitioners should *gauge the young person's views about attending a mental health professional, consider the young person's conceptions of mental health, illness and treatment and the impact these have on service utilisation (Implication 1).*

As suggested by previous work (e.g. (E. Colucci, Szwarc, et al., 2014; Minas, 2007; Pottie et al., 2011)), there is a need for services and practitioners to *be culturally sensitive, respectful and understanding of the person's cultural background (Implication 2).* They must strive to avoid assumptions, learn from the client as an individual and appreciate ethno-cultural and religious contexts and influences. Kleinman and Benson (Kleinman & Benson, 2006) noted that a standard approach to cultural competency risks stereotyping as it does not adequately account for the experience of those who are 'between worlds,' as many young people from immigrant and refugee backgrounds are. Thus, a *nuanced approach to cultural sensitivity* might be more appropriate for this population, i.e. an approach where "the practitioner views the individual in context and turns their gaze toward the interpersonal and sociocultural worlds that the young person has been exposed to, and considers how they have reacted, positioned themselves and constructed their own individual preferences" (Valibhoy et al., 2016, p.22). Whether it is desirable to have *practitioner-client background matching (Implication 3)* was one of the few themes about which practitioners and young people differed. Practitioners suggested matching the young person and professional by ethnic

background, gender and, in some instances, by religious affiliation, while the young people conveyed a fluidity of cultural identities. Two young participants had sought a professional based on language or faith but none saw a professional of the same ethnic background, with some young people commenting that this could be problematic. Evidence for ethnic matching is also mixed (e.g. (Nadeau & Measham, 2006; Ziguras et al., 2000). Yet, there was a shared view that practitioners need awareness of the impact of ethnicity, religion and language on the relationship between the young person and the practitioner (and, as some Study 1 participants noted, in some cases also mode of dress and age). Young refugees will only have a genuine choice of seeing a matched practitioner if workforce diversity is substantially increased.

Although diverse, refugees generally have in common the experience of human rights violations and forced displacement, in addition to being in a cultural and linguistic minority within the host society. While young refugees must be viewed as individuals and not stereotyped, they must still be seen in context. Thus, practitioners need to *be aware of and recognise their young clients' diverse refugee journeys and experiences (Implication 4),* including the possible impact of extreme and prolonged violence and other traumatic experiences, though young refugees expressed the importance of practitioners also recognising their strengths, social support and coping strategies. This implication was stressed also by Watters (2010) who recommended practitioners to be 'politically aware' when working with people from refugee backgrounds, both of the situations that the person has fled but also of the laws and policies impacting on them in the host country. Part of understanding refugee experiences is also to *consider whether, when and how to ask sensitive questions***,** particularly regarding traumatic events *(Implication 5),* as also suggested by Rousseau, Measham and Nadeau (2013). Pottie

(2011) argued that pushing for disclosure of traumatic events may have greater negative than positive effects. Several service users indicated, however, that if the young person felt ready, they could benefit from disclosing traumatic experiences at their own pace.

In both studies, participants recommended *raising mental health literacy and public awareness among refugee youth and their communities (Implication 6)* in order to facilitate access to services. This is particularly important as research shows that Western mental health services and practices may seem alien to young people from refugee backgrounds, who may also have limited knowledge of services available and when and how to access them (see(E. Colucci et al., 2015; de Anstiss & Ziaian, 2010)). English language classes, clubs, recreational groups and ethnic community leaders were suggested as vehicles for such education programs. On the other hand, both service users and providers recommended *increasing the accessibility of services (Implication 7),* for instance, by improving referral/intake processes and eligibility criteria, waiting lists, accessibility of location and co-location with other services. Similar service-level barriers have been identified by young service users from the general population (e.g.(McCann & Lubman, 2012)). Both practitioners and young refugees expressed various ideas to create *enabling and responsive environments (Implication 8)* which, instead of being rigid and sterile, are 'sites of welcome' and able to promptly and adequately respond to the person's needs. The study by Palmer (2006) suggests, for instance, the value of drop-in services and other flexible approaches to appointments. Practitioners explicitly indicated the desirability of *incorporating an outreach approach (Implication 9),* including informal ways to connect and engage young people. Some of the young people expressed their appreciation of services that went to their homes and schools. Practitioners also pointed out the importance of *building relationships between*

agencies (Implication 10), such as between mental health services and schools, other health services and community organisations so that, if the need arises, these agencies are already connected to the mental health services. Similar observations in regards to partnerships (including with religious organisations) were made by Ellis and collaborators (Ellis et al., 2010) and Savin and collaborators (Savin, Seymour, Littleford, Bettridge, & Giese, 2005).

Participants in both studies stressed the importance of trust and that practitioners need to *allow time for trust to develop (Implication 11).* The practical strategies to generate trust with refugees and asylum seekers developed by Procter (2006) could be useful in this context. In some cultural milieus, disclosing personal information outside of the home may be seen as a betrayal of the family (Mpofu, 2002). Furthermore, many refugees have had experiences that have made them suspicious, thus it is essential that practitioners *provide assurance about confidentiality (Implication 12)* and allow for gradual disclosure during the information-gathering process. Issues surrounding confidentiality become even more complex when interpreters are engaged and when interpreters and/or providers belong to the same ethnic/cultural community (E. Colucci et al., 2011). Practitioners indicated that trust and confidentiality are also important at a service-level rather than just at the individual level. Practitioners need to be mindful of ethnicity, religion, community affiliation and gender when *selecting and briefing (qualified) interpreters (Implication 13),* and to ask the young person if they have a preferred interpreter and/or if they wish to continue with the same interpreter in future sessions.

Leavey and colleagues (Leavey, Guvenir, Haase-Casanovas, & Dein, 2007) indicated that family plays a pivotal role in the nature and timing of help-seeking. In Study 2, the young people conveyed that their families were of central importance to them, which they wanted practitioners to appreciate. They also indicated that it was not always best for the practitioner to engage family members. Similarly, practitioners acknowledged variations between families - that in some instances the practitioner can or must involve the family to engage and support the young person while in others the family may become a barrier to engagement. This highlights the need to *consider the role of family and check with the young person before involving the family (Implication 14).* Practitioners more commonly than young people expressed the need to *create links between services and communities (Implication 15),* suggesting that for young people from collectivistic societies, working alongside community members, such as community liaisons or leaders, is important for access and engagement. Previous research has also highlighted the important role that 'brokers', 'advocates' or 'mediators' play in ensuring access and appropriate referral (e.g. (E. Colucci, Chopra, McDonough, Kouzma, & Minas, 2014; Warfa et al., 2006)).

Both young people and practitioners strongly emphasised *rapport and the therapeutic relationship (Implication 16).* The qualities that young people particularly sought and appreciated in their therapist included empathy, compassion, authenticity, respect, trustworthiness, approachability, friendliness, care, skilled listening and understanding. A recent study of traumatised refugees also found that the relationship between the therapist and client (and interpreter) was a main curative factor in itself (Mirdal, Ryding, & Sondej, 2012). *Setting boundaries and expectations (Implication 17)* is an essential component of establishing and maintaining a therapeutic relationship and

requires practitioners to be explicit about what they and the service can and cannot do. Nevertheless, in Mirdal and collaborators' study (Mirdal et al., 2012) it was observed that, while both therapists and interpreters were conscious of the problems related to a possible over-involvement, in this context "compassion goes beyond the Western notion of empathy and (…) it implies the necessity of taking action, such that clients do not stay stuck in their suffering" (p. 444).

A theme that was more central in Study 2 was *tailoring treatment methods and approaches (Implication 18).* Young people expressed diverse views about the various treatment techniques they had experienced. Some felt a sense of improvement from treatment strategies, and some experienced strategies that felt too distressing, ineffective or irrelevant to their main concerns, suggesting the need for practitioners to individualise their therapeutic approach. For example, some experienced relief from sleep-related strategies, while other young refugees felt that being offered formulaic approaches to sleep disturbance conveyed that the practitioner did not understand what occupied their minds while they tried to sleep.

Participants in both studies were critical of practitioners who defined their role narrowly and recommended *addressing the young person's broader concerns and immediate practical needs,* either directly or by referring to the appropriate services *(Implication 19).* There is a large body of literature supporting the need to assist with practical concerns and embrace a holistic approach (e.g. (Allan & Hess, 2010; Behnia, 2003; de Anstiss & Ziaian, 2010; Misra, Connolly, & Majeed, 2006; C. Watters, 2001)). *Continuity of care must be improved* (e.g. within the mental health service and across health, mental health, and social and welfare agencies), *(Implication 20),* especially

because a young person from a refugee background may require assistance from a number of services, making effective care coordination essential. The value of an integrated and collaborative approach to care was has been previously identified, for example, by Ellis and colleagues (Ellis et al., 2010) and Watters (2010).

Finally, both practitioners and young people who had used services identified the need for practitioners to *ask for feedback (Implication 21)* about service users' experiences of all aspects of the service provision, from the interpreter who assists to the time and frequency of appointments, as well as the content and process of sessions. Watters (2008) also recommended 'genuinely' involving young refugees in service delivery planning and evaluation.

Conclusions

The global population of forcibly displaced people today is larger than the entire population of the United Kingdom (UNHCR, 2016). Forced displacement is acknowledged as an important and urgent issue in international public health, and in cultural and global mental health. While countries of resettlement have introduced mental health policies and programs for children and young people from a refugee background, these are based on limited evidence. There is very little refugee-specific research about help-seeking and service utilization and the great majority of the studies focus on specialist mental-health services (see (E. Colucci, Szwarc, et al., 2014)). Moreover, experts have expressed the view that research about mental health service models/systems and services utilisation is high priority (Minas et al., Forthcoming).

The studies that formed the basis for this manuscript (E. Colucci et al., 2011; E. Colucci et al., 2015; Valibhoy et al., in press) aimed to address the gap by researching the perspectives of both service providers and users about barriers and facilitators to mental health service access and engagement among young people who have been refugees. The implications that emerged in these two studies are largely similar to good-practice recommendations from the general/mainstream youth mental health literature; nevertheless, this project was the first attempt to systematically collect and document experiences of service providers and users specifically in regards to young people from refugee backgrounds.

The 21 implications featured in this manuscript provide direction for the development of policies, programs and service delivery for this population, including for the development of training and educational programs. Such initiatives must be directed at young people, refugee communities, agencies and professionals. There is a need to inform young people and communities about 'mental health' and services and to inform service providers about how to best engage young people of refugee background who require assistance (E. Colucci et al., 2011). The refugee mental health research agenda (Minas et al., Forthcoming) provides a guide to researchers on priorities for research that will support program and service development. In particular, as identified by participants in both studies, the perspectives of young people from refugee backgrounds (both those who have engaged with services and those who have not) must be systematically sought and responded to in future service development. As far as this research team is concerned, so far the young people's perspectives have been integrated into academic courses and for professional trainings.

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Table 1 Key themes and implications

Themes and subthemes Study 1	Themes and subthemes Study 2	Implications	Extent of similarity
Concepts of mental health, illness and treatment *When we talk with different cultures, like the new arrivals, or the refugee people, what is their understanding about mental health?*	Understanding contextual influences on service utilisation *It's deeply rooted in our society that if you see a psychologist you're crazy*	1. Gauge (pre)conceptions about attending mental health professionals and consider young person's conceptions of mental health, illness, and treatment	Same / very similar
Cultural competence and sensitivity *(…)if they have the information and they want to come (...) and then the system is not culturally appropriate for them, you can really damage them in [the] long term whether or not they would access the system again* *A trauma-centered approach acknowledges that the trauma is in the room, [the need to] work differently with youth with a trauma history, it's not about having to talk about the trauma*	A nuanced approach to cultural sensitivity *She always mention, "this is in Australia; is that in your culture as well, is that in your background as well?"* *I don't really, yeah, follow my own culture lots. I follow, but not all. People are changing*	2. Convey cultural sensitivity, respect and cultural understanding	Same / very similar
		3. Increase possibilities for background matching, when desirable	Different
	Recognising the impact of psychosocial and traumatic stressors *It stayed, the effects of it, until now.* *Fighting, fighting, never finish (...). It's (...) different like, people living here, people grow up here, and people come from refugee camp (...). When he come here, you know, just remember where he came from. He just, he was suffering, he was sleeping bad, eating bad.*	4. Recognise refugee experiences	Same / very similar
		5. Consider whether, when and how to ask sensitive questions	Same / very similar
Mental health literacy and 'normalisation' *(…) need to educate the community about mental health so they can recognize the signs in a young person. Do not impose Western ideas of mental health and system onto the community otherwise they may not engage. Mental health education [must be] fitted with young people cultural background.*	Public awareness initiatives *Tell everybody that, like let them know there is help (...). I know two people or three people that had suicided (...) refugees and they're young(...). I could've gone to that level but I know that I had help*	6. Raise mental health literacy and public awareness among refugee youth and communities	Same / very similar
Service access (including appointment systems and referrals and intake process) *They might be told to go to a mental health service and, not knowing what's ahead of them, it's easier*	Accessible services *I'm feeling suffering and they can't provide the*	7. Address barriers to service accessibility	Same / very similar

just not to go	*service because of some reason and some formality*		
System flexibility/responsiveness *And we are open 9 to 5, when they are supposed to be in school, not in the doctors' waiting rooms*	Responsive services *Whatever problem in my family or like me happened, I was just talking with X or I ring her, like "I need you, I want to talk with you". And after that I was with her about two years, or more* *X asked me if I want to talk at home or at [service]*	8. Create an engaging and responsive environment	Somewhat similar
Mode/method of service delivery *Outreach was so much more successful than ask people to come to the office all the time particularly with people from different cultural background.*		9. Incorporate an outreach approach	Same / very similar
Relationship with other agencies *(…) we [an English Language School] have developed very close partnership with agencies who we feel have expertise in assisting these kids with those issues. And we believe we don't refer, we work in partnership to support.*	N/A	10. Build relationships between agencies (MH/H services but also schools, social services, etc)	Mentioned by one group only
Trust and confidentiality *(…) the actual referral process and referral forms are a barrier to people getting service, the service that they need. I suppose I'm just thinking recently in a conversation with some Somalian women (…). They needed clear explanation about what that information was going to be used for, to feel okay about disclosing that.*	Trust *You just have to be able somehow to gain the trust and build relationship (...) to be able to win them across (...) it just takes time to um, basically see if you can trust the person* *Confidentiality (...) you don't have that where you came from and it's hard to grasp if you've never experienced it*	11. Allow time to build trust	Same / very similar
		12. Assure about confidentiality	Same / very similar
Working with interpreters *I'll ask the client every time, if I use an interpreter was that good? Did you understand everything? Is that OK if I use the same interpreter next time? I'll really keep a good eye on that.*	Experiences with interpreters *In our community I honestly don't trust them (...) feelings are a joke in our community (...) they'd keep watching their watch (...) they need to be picked (...) the interpreter would leave out some things. (...) they're kind of judging you*	13. Carefully select and brief (qualified) interpreters, with consideration of their ethnic, religious and community affiliation, and gender	Same / very similar
Involvement of the family and family-related issues *Sometime in the mental health system they don't put enough effort into their "how to" work with the family (…). Mental health services don't have time to do it, and it means that young people disengage and they get lost in the system.*	Family conscious practice *It was this idea of not really understanding that family union is different when you have a different cultural background (...). She was surprised that I still lived at home and why I cared so much for [my family]. So it was a bit hard to get through.*	14. Consider the role of family	Somewhat similar

Community involvement and partnership *(…) so if you're working with someone you need to work with the community too.*	Community connections *Tell the actual community leaders (...) maybe make it even compulsory (...) they should tell the community that this [mental health system] exists, that you can get help (...) and tell them in their languages as well and not just in English so they can explain, "yes these people exist."*	15. Strengthen links between services and communities	Different
Mental health professionals' style and approach *(…) if the client sees that you don't care, things are not going to go anywhere* *It's more valued who you are than what you are*	An attuned therapeutic relationship *X was really friendly, wonderful, helpful, she was like sharing everything, emotionally in touch, like she advised me, she listened to me (...) she share my sadness, my happiness (...) not talking to the wall or something to not human* *I was very comfortable with her, she's just like my sister. (...) I would like to continue to come and talk to someone about all the issues, 'cause we don't have a family*	16. Prioritise rapport and the therapeutic relationship	Same / very similar
Expectations *They've got in touch already with many others who have 'tried to help' so better to explain who you are and what you do.*		17. Set boundaries and expectations	Somewhat similar
N/A	Appropriate treatment strategies *It did improve a lot, because every time I came and saw her, she was obviously teaching me new ways about getting some sleep* *They really don't understand us, about our journey, about the life we had, so even if you don't drink or if you don't play with the electronic things, still we can't sleep.*	18. Tailor treatment methods and approaches	Mentioned by one group only
Advocacy (attending to the priorities of the person) *Support them with something that is practical because having an adult to just be talking to a youth is a concept which is foreign to many of them; it proves that you are useful.*	Practical problems *If you really want to help the youth you have to try to find them a job*	19. Hear and address practical problems (holistic/advocacy)	Same / very similar
Continuity of care *They need sort of to have a care coordination plan. Say, for example, once a patient is discharged from mental health service to the GPs, they still need to keep in touch with each other so that if the patient relapses, then the GP can refer back to mental health*	Continuity of care *Every time I went or somebody new came I would not talk (...) 'cause I was feeling better today, so if I was talking to somebody else about what's happened and then I'll go home and then back down to that stage that I was before.*	20. Improve continuity of care	Same / very similar

service immediately.			
Ask for feedback *I'll ask the client every time, if I use an interpreter was that good? Did you understand everything? Is that OK if I use (prefer) to use the same interpreter next time?*	Feedback *Learn from the clients (...). It's good to ask them what they want*	21. Check-in and seek feedback	Same / very similar